



Spanish validation of the “self-perception of burden of care scale”

Validación en español de la escala de auto percepción del peso de los cuidados

Validação em espanhol da escala de auto percepção do peso dos cuidados

María Cecilia Arechabala¹, María Isabel Catoni², Silvia Barrios³, Eugenia Palma⁴

ABSTRACT

Objective: To validate the Spanish language version of the broad “self-perception of burden of care scale” by Cousineau et al. **Methods:** The sample consisted of 161 patients undergoing chronic hemodialysis at five dialysis centers in the city of Santiago - Chile. This scale was translated into Spanish and a pilot test was conducted with ten patients; after this procedure, we developed the final instrument to be subjected to the validation process. **Results:** The reliability of the scale was stable, with fluctuations of the Cronbach’s alpha coefficient of 0.903 and 0.915; we decided therefore to maintain the 25 original items within the Spanish version. **Conclusion:** The overall reliability of the instrument was 0.91, very close to that obtained in the original version (0.93).

Keywords: Caregivers; Patients/psychology; Renal dialysis; Validation studies as topic; Translations

RESUMEN

Objetivo: Validar al español la “Escala de Auto percepción de Carga” de Cousineau (2003) en su versión larga. **Métodos:** La muestra estuvo formada por 161 pacientes sometidos a HDC. La escala se tradujo al español, se realizó una aplicación piloto en 10 pacientes y a continuación se elaboró el instrumento final que fue sometido al proceso de validación. **Resultados:** La confiabilidad de la escala se mantuvo estable al ir eliminando cada uno de los ítems, fluctuando el Alpha de Cronbach entre 0.903 y 0.915. Por lo anterior, se decide mantener los 25 ítems originales en la versión en español. **Conclusión:** La confiabilidad total del instrumento fue de 0.91, muy cercana a la obtenida en la versión original (0.93).

Descriptor: Cuidadores; Pacientes/psicología; Diálisis renal; Estudios de validación como asunto; Traducción (Producto)

RESUMO

Objetivo: Validar, en la lengua española, la versión amplia de la “Escala de Auto percepción de carga de los cuidados” de Cousineau et al. **Métodos:** La muestra estuvo constituida por 161 pacientes sometidos a hemodiálisis crónica en cinco Centros de Diálisis de la ciudad de Santiago – Chile. Esa Escala fue traducida al español y fue realizado un test piloto con diez pacientes; después de este procedimiento, se elaboró el instrumento final sometido al proceso de validación. **Resultados:** La confiabilidad de la escala se mantuvo estable, con fluctuación del coeficiente alpha de Cronbach entre 0,903 y 0, 915, decidiéndose así, por mantener los 25 ítems originales en la versión en español. **Conclusión:** La confiabilidad total del instrumento fue de 0,91, muy próxima de la obtenida en la versión original (0,93).

Descritores: Cuidadores; Pacientes/psicología; Diálise renal; Estudos de validação como assunto; Tradução (Produto)

¹ Master’s in Psychology, Escuela de Enfermería, Pontificia Universidad Católica de Chile.

² Master’s in Philophical Foundations, Escuela de Enfermería, Pontificia Universidad Católica de Chile.

³ Master’s in Public Health, Escuela de Enfermería, Pontificia Universidad Católica de Chile.

⁴ Nephrology Nurse Specialist, Pontificia Universidad Católica de Chile

INTRODUCTION

Those persons undergoing dialysis are often confronted with stressful situations, be they related to their image or their functionality. Living with a family member may help to improve the perception of social support and to deal more effectively with the complications arising from the disease or its treatment⁽¹⁾.

Patients with end stage renal disease (ESRD) often depend on other people to perform activities of daily living and meet the needs arising from medical treatment. People who have a responsibility to assist in these activities (care) are called caregivers⁽²⁾ and frequently are relatives or friends of the patient who also provide daily emotional and psychosocial support⁽³⁾.

Caregivers develop an important role in the life of the majority of patients undergoing hemodialysis (HD), and the experiences with respect to them are different for each person. In general, they are described as a support, but they also acknowledge negative experiences. A frequent experience is related to the caregiver's perception of dependence. Some patients accept the dependence imposed by their illness and express their satisfaction for the support that is offered by their caregivers, while others consider the dependence as having been imposed by caregivers and not by the disease. Caregivers also have been described by patients as a source of difficulty and distress⁽⁴⁾.

Despite the fact that care is framed within a didactic relationship between the caregiver and whomever receives the care, studies usually focus on the care provider. Less attention has been given to the feelings of the recipient of the care, who sometimes feels that she has become a burden to others. This feeling has been called "self-perceived burden", and has been defined as: "a multi-dimensional construct arising from the care-recipients' feelings of dependence and the resulting frustration and worry, which then lead to negative feelings of guilt and being responsible for the caregiver's hardship"⁽⁵⁾.

Cousineau et al.⁽⁶⁾ conducted an investigation with the objective of identifying the elements that should form part of a scale of self-perceived burden of care. Although the authors concluded that the subjective perception of burden consisted of three domains – concerns about the physical effects of caring on the health of the caregiver, about the effects on emotional health and apprehensions concerning the financial costs of care – in the factor analysis the scale behaved as a single dimension.

The present study had the objective of validating in the Spanish language the *Self-Perceived Burden Scale* of Cousineau et al., in the long version⁽⁶⁾. The validation of this scale constitutes one step of the research entitled "Depression and self-perception of the burden of care in hemodialysis patients and their caregivers", which

was conducted in five hemodialysis centers in the city of Santiago, Chile⁽⁷⁾.

METHODS

Participants

The sample consisted of 161 patients undergoing chronic hemodialysis (CHD) in five dialysis centers (DC) in Santiago, Chile. We applied the inclusion criteria to all patients of these DC, being careful to include users from all shifts, since this characteristic is relevant to the independence of patients.

The criteria for inclusion in the study were: having undergone CHD for a period equal to or greater than three months; not presenting cognitive impairment (evaluated using the Folstein mini-mental); recognize having a primary caregiver; and, voluntarily agree to participate in the study by signing an informed consent.

Trained research assistants applied the instrument to patients using an interview process during the CHD procedure.

Instrument

The *Self-Perceived Burden Scale* of Cousineau et al.⁽⁶⁾ had the objective of identifying patients with emotional problems related to feelings of being a burden on their caregivers. This instrument has two versions in English: a long version with twenty-five items that has demonstrated good internal consistency by obtaining a Cronbach's alpha of 0.92; and, an abbreviated version of ten items with a Cronbach's alpha of 0.85.

The version validated in the present study was the original, with 25 items. It contains 25 assertions of patients' feelings with respect to what it means to care for their primary caregiver. These include physical and economic aspects and primarily emotions related to their caregiver. The responses are given using a five-point Likert type scale, ranging from: 1 = almost never to 5 = almost always.

The total possible score ranges from 0 to 100⁽⁶⁾. The interpretation establishes a direct relationship between the score and the patient's perceptions regarding the significance of the burden – of care – on the primary caregiver, i.e., the higher the score, the higher the perceived caregiver overload.

The validation of the scale was conducted with the permission of the authors. We proceeded to perform the translation and back translation of the instrument as mentioned above. These processes were conducted by two bilingual teachers in an independent manner. The first translation was to take the original version and translate it into Spanish (translation), and the second was

to take that Spanish version and translate it back into the English (back translation).

A pilot study was conducted using the Spanish-language scale with ten patients undergoing CHD, with the same characteristics of the final sample but from a different DC than those which would be part of the study. This procedure showed that it was necessary to make small modifications of the language to improve understanding of the items. After this process, the final instrument was developed which was submitted to the validation process.

Statistical Analysis

For analysis, we used the SPSS program, version 19.0. We calculated statistical analysis of central tendency, performed factor analysis, and calculated internal consistency using Cronbach's alpha.

RESULTS

Patient characteristics: 40% were women, with an average age of 56 ± 14.9 years. In 61.5% of the cases

the cause of ESRD was diabetes mellitus or arterial hypertension. The average number of comorbidities was 2 ± 1.2 diseases. The age at CHD was, on average, 61 ± 56.6 months, with a median of 48 months.

Characteristics of the primary caregivers: 75% were women, with a mean age of 50 ± 16.1 years. They had been providing care related to their family for 59 ± 54 months, with a median of 48 months. The time that was devoted to this caregiving activity was an average of 18 ± 8 hours daily. All of the caregivers had some type of blood relationship with the patient, with the majority being spouses.

Item performance

The study of the behavior of the items was performed using the classical theory of measurement. It is possible to observe in Table 1, that the majority of the items (22 of 25) showed significant correlations (> 0.3), among the items and the total score obtained on the scale.

The reliability of the scale was calculated by means of the Cronbach's alpha, which remained stable with the elimination of each of the items, ranging between

Table 1. Item analysis of "Self-Perceived Burden Scale" of Cousineau et. al., original version

	Item	Correlation – test items	Cronbach's alpha without the item
1	I worry that my caregiver will be exhausted by the requirements of taking care of me.	0.45	0.908
2	I worry that the health of my caregiver may affect my health.	0.23	0.912
3	I worry that my caregiver is overloaded by taking care of me.	0.60	0.905
4	I worry that my care costs my caregiver much money .	0.56	0.906
5	I worry that my caregiver needs to stop doing other things to help me.	0.57	0.905
6	I worry that I will not be able to give back or pay my caregiver for everything that has been done for me.	0.54	0.905
7	I feel guilty because of the demands made upon my caregiver.	0.53	0.906
8	I worry because my caregiver has to assume many responsibilities for me.	0.60	0.905
9	I feel guilty because my caregiver has to change plans in order to help me.	0.72	0.902
10	I worry that my caregiver has lost control of her life to care for me.	0.66	0.904
11	I worry that my needs are so demanding that my caregiver can not handle them.	0.62	0.904
12	I worry that when I ask for help I put too much pressure on my caregiver.	0.50	0.907
13	I worry that with everything that has to be done for me, the person that cares for me cannot keep doing it.	0.63	0.904
14	I worry that my caregiver is helping me beyond her capacity.	0.68	0.903
15	I find it easier to ask for help from my caregiver when I can give something back.	0.38	0.909
16	I am concerned that the demands of my care have deteriorated the relationship between him (her) and me.	0.39	0.909
17	I worry that I constitute a problem for my caregiver.	0.61	0.905
18	To receive help from others makes me feel that they worry about me.	0.04	0.914
19	I worry that because of my illness, my caregiver (s) is doing many things at the same time.	0.71	0.902
20	I worry about the negative effects that my illness can have on people around me.	0.52	0.906
21	I have confidence that my caregiver can manage the demands my care requires.	-0.12	0.915
22	I find it easier to accept the help offered to me than to ask for help.	0.71	0.913
23	I worry that by taking care of me my caregiver feels overwhelmed.	0.68	0.903
24	I think I make things difficult for my caregiver.	0.60	0.905
25	I feel that I am a burden to my caregiver.	0.68	0.903

0.903 and 0.915. This indicates a good reliability and stability of the instrument, so it was decided to maintain all 25 of the original items. The overall reliability of the instrument calculated by means of the Cronbach's alpha coefficient was 0.91, very close to that obtained in the original version (0.93).

Exploratory and confirmatory factor analysis

The authors had constructed the scale based on a conceptual model of three factors. Therefore, we performed an exploratory factor analysis to identify the factors of the reference model, namely that of identifying the latent variables which underlie the items. We began with the original solution proposed by Cousineau et al., observing that in the three-factor rotated matrix (Varimax method), the items clearly were not distributed around one conceptual variable. The same procedure was repeated for a two-factor model obtaining the same result.

The three-factor model explained 46% of the variance, while the one with two explained 41% of the

variance. Therefore, as in the original validation of the instrument, it was decided to opt for a simpler solution, namely, that of a single dimension (Table 2).

Because it is a continuous rating scale and it would facilitate understanding of the results to establish the cutoff point of the category "high perception of overload", we proceeded to establish this point arbitrarily at one standard deviation above the average obtained by the sample.

The scores obtained by the sample on the scale of self-perception of burden in this study were: mean of 52.8 ± 23.9 (range of 8-100 points). According to these results, patients who scored greater than or equal to 76.8 perceived their caregiver highly burdened with their care. There were 20.37% (confidence interval of 95% [CI 95%], 14.98 - 27.22) of the patients of this study who were located on the cutoff point, which meant that they perceived that their caregivers were overloaded with their care.

The average score on the scale for the men was higher than the women (53.3 versus 52.1), that is, they felt that their caregivers were more burdened, however this difference was not statistically significant ($t = 0.32$, $p = 0.75$).

Table 2. Factor loading of the items (Varimax rotation). "Self-Perceived Burden Scale" of Cousineau et al., two and three factor models.

Item	Three factors			Two factors	
	I	II	III	I	II
1 I worry that my caregiver(s) will be "exhausted" by the requirements of taking care of me.	0.11	0.69	0.03	0.23	0.62
2 I worry that the health of my caregiver may affect my health.	-0.05	0.05	-0.10	0.01	0.54
3 I worry that my caregiver is overloaded by taking care of me.	0.28	0.75	-0.07	0.36	0.71
4 I worry that my care costs my caregiver much money .	0.68	0.09	-0.12	0.61	0.10
5 I worry that my caregiver needs to stop doing other things to help me.	0.51	0.40	-0.18	0.48	0.42
6 I worry that I will not be able to give back or pay my caregiver for everything that has been done for me.	0.48	0.34	0.03	0.52	0.28
7 I feel guilty because of the demands made upon my caregiver.	0.62	0.13	0.01	0.61	0.09
8 I worry because my caregiver has to assume many responsibilities for me.	0.60	0.30	-0.09	0.58	0.29
9 I feel guilty because my caregiver has to change plans in order to help me.	0.65	0.42	-0.04	0.66	0.38
10 I worry that my caregiver has lost control of her life to care for me.	0.60	0.34	0.10	0.65	0.26
11 I worry that my needs are so demanding that my caregiver can not handle them.	0.74	0.08	0.18	0.76	-0.01
12 I worry that when I ask for help I put too much pressure on my caregiver.	0.621	0.24	0.39	0.71	-0.14
13 I worry that with everything that has to be done for me, the person that cares for me cannot keep doing it.	0.60	0.32	0.11	0.64	0.24
14 I worry that my caregiver is helping me beyond her capacity.	0.58	0.45	-0.05	0.60	0.42
15 I find it easier to ask for help from my caregiver when I can give something back.	0.61	-0.07	-0.33	0.46	0.04
16 I am concerned that the demands of my care have deteriorated the relationship between him (her) and me.	0.45	0.06	0.39	0.55	-0.10
17 I worry that I constitute a problem for my caregiver.	0.43	0.54	0.05	0.51	0.47
18 To receive help from others makes me feel that they worry about me.	0.08	0.08	-0.65	-0.12	0.32
19 I worry that because of my illness, my caregiver (s) is doing many things at the same time.	0.47	0.65	0.06	0.56	0.56
20 I worry about the negative effects that my illness can have on people around me.	0.33	0.50	0.39	0.51	0.30
21 I have confidence that my caregiver can manage the demands my care requires.	-0.05	-0.12	-0.38	-0.18	0.03
22 I find it easier to accept the help offered to me than to ask for help.	0.03	0.14	-0.25	-0.21	0.22
23 I worry that by taking care of me my caregiver feels overwhelmed.	0.49	0.56	0.26	0.63	0.41
24 I think I make things difficult for my caregiver.	0.62	0.22	0.36	0.73	0.05
25 I feel that I am a burden to my caregiver.	0.63	0.35	0.01	0.68	0.27
% of variance explained	25.34	15.16	6.09	28.96	12.14

Limitations of the study

One of the limitations of the present study is that validation of the instrument was performed on a sample of patients with ESRD, which restricts its application to this group of people. It would be advisable to validate it in other groups of chronically ill patients to extend its applicability. Another limitation lies in that the application of instruments to patients took place during the session of CHD, a factor that could affect privacy during the interview and increase social desirability in responses. However, this is common practice, given the amount of time patients spend in the DC. Moreover, it is suggested that the validation of the short version of this instrument should be completed to avoid the application of tools with many items, especially in those studies that consider several variables.

DISCUSSION

It is recognized that kidney disease and its treatment can have a high impact on caregivers of these patients, specifically a high degree of tension, anxiety, fatigue and deterioration of family relationships⁽⁸⁻⁹⁾.

Moreover, there is no doubt that the role of caregiver is very stressful, therefore it is associated with higher levels of depressive symptoms and with poor health. Normally those who assume this work are relatives and primarily spouses. Because the marriage relationship is characterized by interdependence and reciprocity, it is important to know the views on these responses, attitudes and emotional states of each of the spouses in order to strengthen the relationship between them⁽¹⁰⁾.

The increase in technology and in treatments has resulted in the consequence of increased life expectancy of people with ESRD and with it the emergence of a greater number of comorbidities, which may affect their independence and thus involve a greater need for care⁽¹¹⁾.

The degree to which a chronically ill person feels he is a burden to his caregivers may complicate this relationship, which can provoke anxiety and depression, which may interfere with treatment compliance. There are also studies which show that the feeling of being a burden can influence the use of measures to prolong life, as well as increasing the probability of asking for euthanasia or having suicidal ideas⁽¹⁰⁾.

Perceiving oneself to be a burden on others evokes a series of negative emotions and negatively affects self-esteem. The necessities of care often lead to feelings of guilt, regret, frustration and concern about the impact these can have on others⁽⁵⁾.

The contribution of this study is the Spanish validation of an instrument that allows us to understand the perception of overload from the perspective of the person receiving care⁽⁷⁾. This can sometimes be

the reason for non-adherence of patients or problems in relationships between him and his caregiver. If the professionals who provide care to patients with ESRD know the stress points that exist in this dyad, it will allow them to design effective interventions to alleviate the anguish from being a burden and to improve communication.

In addition, they could anticipate this consequence of the care, implementing measures to help the caregiver in a manner that diminishes the overload and establishing interventions directed to the patient in a manner to improve the relationship between them. The *Zarit Overload Scale* has made a significant contribution to research in this area (validated in Spanish in its original version, and abbreviated by Breinbauer et al., 2009), so as to have the information needed to design a model of care that considers the evaluation of the burden of care within the patient-caregiver dyad, for planning specific interventions aimed at supporting them both and strengthening their relationship⁽¹²⁾.

The study within which the scale of Cousineau et al. was validated⁽⁶⁾ assessed the patient's perception of social support from family and friends. The analysis performed on the two scales showed an inverse correlation between both variables, but not significant ($r = -0.112$, $p = 0.15$). That is, the higher they perceived their caregiver's overload, the lower the patient perceived to have his support.

CONCLUSION

The Spanish validation performed on the "Self-Perceived Burden Scale" showed that the 25 items that comprised it were not structured around the original conceptual model of three factors (physical, emotional and economic), similar to what happened in the validation of the original version. It is because of this that it was established as a unidimensional scale.

The analysis of the items determined that the internal consistency did not vary with the elimination of some of the items, which is why we maintained the original structure with 25 items.

Metric properties of the instrument were determined, obtaining good validity and internal consistency similar to the original instrument.

These results may have a high impact in clinical practice since it provides the multidisciplinary team providing care to patients with ESRD a valid and reliable instrument that assesses their perceptions with regard to the care burden and implications for the family.

APPRECIATION

Study funded by the Research School of Nursing, Pontificia Universidad Católica de Chile.

REFERENCES

1. Madeiro C, Lopes P, Melo I, Ribeiro A, Teixeira F. Adesao de portadores de insuficiencia renal crônica ao tratamento de hemodialise. *Acta Paul Enferm.* 2010; 23 (4):546-51.
2. Ávila-Toscano JH, García-Cuadrado JM, Gaitá N-Ruiz J. Habilidades para el cuidado y depresión en cuidadores de pacientes con demencia. *Rev Colomb Psicol.* 2010; 19(1): 71-84.
3. Suri R, Larive B, Garg A, Hall Y, Pierratos A, Chertow G, et al. Burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials. *Nephrol Dial Transplant.* 2011; 26(7):2316-22.
4. Krespi MR, Bone M, Ahmad R, Worthington B, Salmon P. Hemodialysis Parents' evaluation on their lives. *Turk Psikiyatri Derg.* 2007; 19(4): 365-72.
5. McPherson C, Wilson K, Murray MA. Feeling like a burden: Exploring the perspectives of patients at the end of life. *Soc Sci Med.* 2007;64(2):417-27.
6. Cousineau N, McDowell I, Hotz S, Hebert P. Measuring chronic patients' feelings of being a burden to their caregivers: Development and preliminary validation of a scale. *Med Care.* 2003; 41(1):110-8.
7. Arechabala MC, Catoni MI, Palma E, Barrios S. Depresión y auto percepción de la carga del cuidado en pacientes en hemodiálisis crónica y sus cuidadores. *Rev Panam Salud Pública.* 2011; 30(1):74-9.
8. Beanlands H, Horsburgh ME, Fox S, Howe A, Locking-Cusolito H, Pare K, et al. Caregiving by family and friends of adults receiving dialysis. *Nephrol Nurs J.* 2005;32 (6):621-31.
9. Belasco AG, Barbosa D, Bettencourt AR, Diccini S, Sesso R. Quality of life of family caregivers of elderly patients on hemodialysis and peritoneal dialysis. *Am J Kidney Dis.* 2006; 48(6):955-63.
10. Wilson-Genderson M, Pruchno RA, Cartwright FP. E. Effects of Caregiver Burden and satisfaction on affect of older end stage renal disease patients and their spouses. *Psychol Aging.* 2009;24 (4): 955-67.
11. Harris TI, Thomas CM, Wicks MN, Faulkner MS, Hathaway DK. Subjective burden in young and older African- American caregivers of patients with end stage renal disease awaiting transplant. *Nephrol Nurs J.* 2000;27(4):383-91.
12. Breinbauer KH, Vásquez VH, Mayanz SS, Guerra C, Millán KT. Validación en Chile de la Escala de Sobrecarga del Cuidador de Zarit en sus versiones original y abreviada. *Rev Méd Chile.* 2009;137(5):657-65.